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ABSTRACT

Six issues of the newsletter address practical matters for parents of handicapped children. The first issue examines behavior and offers suggestions such as avoiding inconsistency and idle threats while holding reasonable expectations. The second issue continues the discussion on behavior with ideas for disciplining the child fairly but effectively, especially regarding eating habits, bedtime behavior, and public behavior. The third issue focuses on enhancing speech and communication skills and includes a review of normal speech development and a discussion of ways parents can help promote speech. The fourth issue emphasizes the value of play, offering suggestions for indoor and outdoor play. Guidelines for preparing the young child for school and rights of the parent of a handicapped child are summarized in the fifth issue. The final issue focuses on relationships within the family of the handicapped child. Additional columns in each issue give a psychologist's viewpoint on siblings, acceptance of the child's disability, and hints for stress management. (CL)

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Special Parent ★Special Child

Practical pointers for parenting handicapped children

VOL. 1, NO. 1 JANUARY/FEBRUARY 1985

BEHAVIOR

In this issue, part 1 of a 2 part series, you will be given pointers on how to discipline your handicapped child fairly, yet effectively.

Although your child has a handicapping condition, this does not mean he cannot learn to behave. The fact that your child is handicapped does not mean he has to misbehave or, even worse, that he is impossible to control. When your child learns to behave in acceptable ways he can be included more and more in the world. The world will not change to meet your child's whims. Like it or not, your child is the one who has to learn to conform to the world to the best of his ability. Your child's inability to function with other people or to exhibit embarassing public behavior is an area most painful to all members of the family.

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How did he get this way?

Perhaps you have developed ambivalent feelings towards your handicapped child. This is only natural. After all, you've received a shattering blow when doctors or other professionals have diagnosed your child as handicapped. You love him, true, but feel guilty about setting limits. While you might have established ground rules for your normal children, you're not sure your handicapped child knows or understands what is expected of him. This leads to confusion and very often you wind up unintentionally making excuses for your child's misbehaviors. "Johnny has a problem, he can't help the way he acts," you soon find yourself telling others. The handicapped child often feels insecure and threatened by your own inability to control him. This leads to a continuing cycle of confusion, mismanagement and escalating misbehaviors. Above all else, handicapped children need parents who **limit as well as love.** Try not to see the handicap your child has, but see your child as an individual capable of being reached and taught — a "can do" member of the family, like everybody else.

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Do's and Don'ts

. . . Do have a schedule

Order is very important to your child. Through external order he is better able to control himself. Handicapped children often invent order and ritual of their own. For example, does your child line things up, insist on wearing the same article of clothing, won't sleep unless the shade is set a certain way, won't eat without his special cup, get upset if you rearrange furniture or even react adversely if you buy a new car? From this kind of ritualistic behavior and sameness your child finds security. He is asking you, in effect, to regulate his external environment. He is really seeking a **schedule** as a way of relieving his own inner turmoil. Your child is bound to feel more comfortable if you are able to provide a schedule of regular mealtimes, bathtimes, bed times and TV times.

. . . Don't be inconsistent

When you make a schedule and rules for the child, the child has the right to expect consistency from you. Exceptions may have to be made because adults have a busy life, with many demands on them. It isn't always possible to do the same thing in the same way every day. You might have to compromise in actual practice. But too much unevenness from day to day creates problems. Show the child you can be trusted. When changes occur, make sure you give clear, simple explanations. "This time we have to do it this way." Don't use long explanations or discussions because most of it will be wasted on him. Differences between you

and your spouse create inconsistency, too. Get together on what you ask of the child. It helps if you both use the same words, the same tone of voice and set the same limit.

. . . Do tell him the next step in the schedule

This helps your child keep track of things. He's absorbed in his own world. He doesn't realize you must get dinner on and doesn't care. So say "after the next swing on the swing we go in," or "bath is over, now it is time to go to bed." For some children it helps to be even more explicit: "First bathtime, then pajamas on, then lights out and into bed."

Mean what you say. The chances are he'll follow along. If you hesitate or give in sometimes and not others, he'll try to see how far he can go.

. . . Don't give in

Once you have gotten together and decided on what your family rules and limits are, stick to them. For example, if you have decided bedtime is at 7 p.m., stick to that

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TEACHER TALK: HELPING YOUR CHILD RECOGNIZE COLORS

Color code your child's world. In the morning when he dresses talk about his "blue pants, white socks, etc." As he eats, mention "green lettuce, white milk." Feature a color of the week—red, for instance. Serve liquids in a red cup, make strawberry Jello, talk about red apples, ask your child to select the red crayon. Insure instant success by pointing to the correct crayon until you are sure he understands what you want. Get paint chips from your paint store and make color books from them. Have a sticker book and reward your child with red stars.

decision even if your child pleads or, worse yet, tantrums. Stay calm. Say over and over clearly and using the same prearranged words, "It's bedtime." Sometimes it pays to rehearse by repeating the same calm instructions before the actual event. You might have to firmly place your child in bed and put up with some nightly howls of protest. Stick to your guns. Gradually your child will learn that in your consistent way you mean what you say. Shouting and spankings will become unnecessary. Gradually he'll follow along and soon it will become routine.

. . . Don't make idle threats

Do not threaten your child with consequences or punishments that are impossible for you to carry out. If you wish your child to finish his dinner, make a rule that if he doesn't finish there will be no TV. Mean what you say and stick to it. Don't say "if you don't finish your dinner I'll send you to the moon." This is meaningless and will not get the desired results.

. . . Do have reasonable expectations

Your child's actions seem logical and reasonable to him as he perceives the situation. Put yourself in his position and you may understand his baffling behavior.

Remember, he has a limited knowledge of the world to begin with, a different idea of what is important and fuzzy notions about time. For instance, he might not understand what is meant by tomorrow, later on, etc. Also he has to learn things in sequence. He doesn't automatically transfer what he's learned from one set of circumstances to another. For example, you wish to teach your child to stay away from your hot stove. Telling him once, "No, stop, don't touch, hot, hands down" isn't enough. The command must be repeated over and over patiently and calmly in the same tone of voice. Even if the words are plain enough and he has finally learned not to touch **your** hot stove, he might touch his grandmother's hot stove. He is unable to transfer learned behavior from one situation to another. Remember this type of behavior is normal for your handicapped child. Although it's frustrating it is necessary to train and retrain as each new situa tion arises.

. . . Do use the right words

Words we use give children a pattern for behavior. "Take the dish to the table" is a positive action instruction. It tells your child exactly what to do. "Don't make that noise" stops him without giving him an appropriate alternative. "Be good" or "stop that" are equally ineffective because they are vague. A firm quiet voice is most effective. Touch him lightly to get his attention. Look at him, bend to his eye level. If you shout across the room he may not be able to catch all your words. If you use a loud voice, he may not listen anymore. He'll tune you out as you yourself do with a loud TV. Handicapped children often can't sort out different noises or blot out background sounds like the hum of a furnace or fan motor. Each new sound commands his attention and his mind dashes from one to another. Your child's behavior might rise in crescendo with the noise around him, becoming more and more confused and excited. Remember to be as concrete as possible in giving instructions to your child and try to provide as calm and quiet an environment as possible.

NEXT ISSUE:
BEHAVIOR, PART II

You are on line in your local supermarket with $80 worth of groceries in your cart. The ice cream is about to melt and your handicapped child chooses this moment to tantrum so loudly you wish the floor would open up and swallow him, you and the cart!

How to avoid this and other pitfalls in rearing your special child are coming in the March/April issue of Special Parent/Special Child.

. . . Don't get frustrated.

Today your child refused to stay in bed again. He's been doing it for days, even weeks. You feel he should be punished not only for this particular misbehavior but for all the other things that have gone wrong. This often may include the frustration you feel in having a handicapped child. It is the "last straw." Thinking like that leads parents to harshness and severity. Handle one problem at a time so you can handle the child without overdoing it. Bedtime first, bad day second, overwhelming feelings about having a handicapped child another time. You can't solve everything with one spanking.

You might just want to throw up your hands and lose faith in the slow teaching method. This is the day to look at the situation as it appears to the child. Look behind the behavior for reasons:

1. Is there illness, hunger, fatigue?
2. Do you ask too much? Leave temptation at hand?
3. Do you compare him unfavorably with brother or sister?
4. Are your instructions confusing?
5. Is his misbehavior a bid for attention?

. . . Don't lose control

It's normal and natural to feel angry when your handicapped child misbehaves. However, feeling angry, and losing control of yourself are two entirely different things. It's best to firmly, even strongly, tell your child in simple language that the misbehavior is wrong. Remember to try to channel his inappropriate behavior into something constructive. Remember also that handicapped children seem to take a great delight in getting a rise out of you. Your reddened face and hysterical tone of voice also mean that your child has your undivided attention! If you simply repeat firmly to your child that the behavior is wrong, while showing your child that you are the one in control of the situation and not him, chances are he will get bored of the activity and go on to something else.

. . . Don't ignore your child when he is good

Being good sometimes results in being forgotten. Being bad is guaranteed to bring someone into the picture and a spanking isn't too big a price to pay when you're lonely or bored, especially if you're handicapped. Don't take this good behavior for granted; show pleasure in individual acts. For example, "you did a good job eating your lunch today," or "I like the music you are making" means more than "what a good boy" or "be a good girl."

. . . Don't get overwhelmed

Individual battles seem overwhelming at times. But in the long run, the slow, steady approach of teaching and reteaching will succeed. When you use this method of teaching behavior you will stop being in such a hurry. You can give in occasionally and won't feel overwhelmed by past mistakes, guilty feelings and loss of temper now and then. You can laugh over the problem instead of bursting into tears. You won't worry about "losing face" or "letting him get out of hand." You'll be able to smooth things over and minimize the struggles.

PRACTICAL POINTERS

1. Stop feeling guilty about setting limits for your handicapped child.

2. He can learn family rules as well as your normal child if you gear things to his level.

3. Rules and limits must be understood by your child.

4. Make sure your explanations to your child are in simple language, delivered in a low tone of voice.

5. Rules must be enforced.

6. Once you make a rule or set a limitation, enforce it every time until the behavior is learned.

7. Get his eye contact before issuing an instruction.

8. Have regularly scheduled meal times, bath times, bed times, TV times.

9. Always tell him the next step in his schedule.

10. Don't give in for the sake of short-time peace.

11. Don't be moved by your feelings of sympathy over your child's condition to give him "just one more chance."

12. Provide a calm, quiet environment as much as this is possible.

13. Praise and recognize your child's good behaviors.

14. Enhance your child's self-esteem by allowing him to help as much as he is able.

15. Expect good behavior and very often you will get it.

Psychologist's Corner: THE "OTHER" CHILD

by George Popper, Ph.D.

What's it like to have a handicapped brother or sister? How will my "normal" child be affected if his sibling has a problem? These are among some difficult questions confronting parents. Often, a special child is not an only child and this creates additional stresses on the family. Special children have special needs. There are all those trips to the doctors and psychologists, not to mention school. Parents sometimes feel that their disabled child requires greater attention and protection and often they're right. But what of the "other" child?

Help your normal child to comprehend the nature of his sibling's problem in a manner that is understandable to him. All too often parents, because of their own fears and prejudices, try to conceal the true nature of the problem. A bright child can sense when something is wrong and excluding him may add to feelings of rejection. Listen to your child and allow him to share his concerns and uncertainties with you without fear that he might be punished for what he says. Bear in mind that all your children need to know you love them and trust them enough so they'll confide in you.

What should you say when your child asks, "What's wrong with my brother or sister?" What you say depends on your child's level of understanding. Without being overly technical, tell him honestly what the problem is and how much you appreciate his help and understanding. Allow him to participate. Even in the best of families siblings have fights. Unlike adults, children have very concrete and definite concepts of fairness and right and wrong. Even though your normal child has grown to love and ac-

IN FUTURE ISSUES LEARN ABOUT:

- Those Psychological Tests: What Do They Mean?
- Speech: Ways to Encourage Your Child's Ability to Communicate
- Your Child and School: Getting Your Child and Yourself Through The Special Education Maze
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cept his handicapped sibling, he still gets angry when his homework or favorite toy has been destroyed. Understand the reason for the anger and hurt and be fair. Just as you would not accept inappropriate behaviors from your normal child, you should not accept them from your special child. Like all children, they need to learn the consequences of what they do. A perception of fairness and evenhandedness goes a long way toward having all your children feel accepted and loved.

Another issue often raised involves friends. Children can be unthinkingly cruel and words such as "retard" or "weirdo" can hurt deeply. As children grow, their friends become more important than their parents and peer approval becomes a strong motivator. Parents need to understand this. Children need their friends and their space. Forcing your normal child to constantly take his disabled sibling wherever he goes with his friends does more harm than good. For one thing, it can engender resentment and anger rather than love and understanding. Helping your handicapped child to develop his own circle of friends through such things as organized groups is a far better alternative.

Having a special brother or sister can indeed be a rewarding experience. It teaches a child to become a compassionate and caring human being. All he needs is the chance to learn.

THE READER ASKS . . .

QUESTIONS AND ANSWERS

We invite inquiries or hints from our readers. If you have a question, a problem or comment about any aspect of parenting special children, write to:

Special Parent/Special Child
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Q. My four-year-old daughter has an annoying habit—she doesn't make eye contact. She's always looking sidewise or turning her head to one side. My husband tells me to stop overreacting and to ignore it. Have you any suggestions?

A. Eye contact **is** very important. Tell your husband it is considered primary for social growth and learning. When you want to get your child's attention, bend down to her eye level. Cup her chin gently with your hand. Blow gently on her face to get her attention. Every time she responds, praise her with a gentle pat, a small food treat. Work in front of a mirror for short periods. Stand behind your daughter, naming and pointing to her features. It might be necessary to whistle or make strange faces to get her to focus on the mirror. Make it fun and soon she will get into the habit of looking directly at people.

Q. I have a child who can't fall asleep. We've tried a night light, bedtime stories, allowing him to get in bed with us, letting him stay up late to tire him out. Nothing works—has anyone solved this problem?

A. Your remedies perpetuate your child's nighttime misbehaviors. Your child has your undivided attention all night long! Try keeping to a bedtime routine. Put your child gently but firmly to bed. Don't respond to tears, whines, requests, etc. Be consistent even though there will be an **increase** in the misbehavior before there is a decrease. Your child is testing you; but if you do not respond either negatively or positively the nighttime misbehavior will subside. Once your child senses you are in control of the situation, bedtime will not be such a problem.

The next issue of SPECIAL PARENT/ SPECIAL CHILD will explore in detail specific sleep problems.

Illustrations by Leah Spring

Special Parent ★Special Child

Practical pointers for parenting handicapped children

VOL. 1, NO. 2 MARCH/APRIL 1985

BEHAVIOR

In this issue, part 2 of a 2 part series featuring how to discipline your handicapped child fairly, yet effectively, you will be given pointers on eliminating the behaviors that cause the most family stress: bad eating habits; bedtime behavior; and embarrassing public behavior.

Parents are in charge

Be aware that reducing inappropriate or nuisance behavior in your special child is a gradual process. Your youngster cannot easily stop those irritating behavior patterns he's had for years. Your first attempts to reduce the misbehavior will often lead to an **increase** in the very behavior you are trying to eliminate. Remember that this is normal. It is important for you to stay calm, be consistent and not to give in sometimes and not others. Make sure you give your special child the impression that you are the one in charge and that inevitably your will is stronger. Handicapped children feel more secure and behave more appropriately in households where parents can limit as well as love!

Eating habits

The giving of food is the primary nurturing bond between mother and child, normal or otherwise. It's natural for anxieties to arise over your child's eating habits, especially when he's handicapped. Perhaps your special child was a poor eater, had difficulty swallowing or refused anything but certain foods. Perhaps you gave in to his demands or ignored his dreadful table manners for the sake of peace and quiet or because of your own qualms about meeting his nutritional needs. No matter the reason—if your special child is a problem eater, it is never too late to instill good eating habits. Mealtime at your house can become an enjoyable experience for the entire family.

Do's and Don'ts

Do have a consistent mealtime schedule . . .

. . . as much as this is possible. Handicapped children feel secure when events (yes, even dinner) occur on time. A quiet, hassle-free mealtime environment is best. Having his own place at the table is also helpful for your special child.

Start gradually . . .

It's a good idea to select that particular eating habit that is the most troublesome instead of trying to turn your bad eater into a gourmet overnight. Work on one of the applicable behaviors listed and when you achieve success with one problem, work on the others one at a time.

Is your special child still drinking out of a bottle long past weaning age?

- Do throw away all bottles in full view of your youngster.
- Do offer small quantities of milk in a small glass.
- Don't plead, beg or offer extravagant treats. Calmly offer him his milk or other fluids and ignore such signs of temper as spilling or dribbling.
- Don't become worried that your child will develop calcium deficiency overnight. He won't!
- Don't worry about dehydration—there is ample liquid in food.
- Do make sure that siblings and other family members set an example and drink at the same time as your handicapped child.
- Don't become alarmed or frustrated if your child continues to dribble his milk. Ignore this behavior consistently. He will soon tire of this activity if you don't pay it a lot of attention. Make sure there are only small quantities of liquid in his glass or cup at any given time and you can avoid the floods!
- Do praise your child warmly whenever he drinks appropriately, even if it's just a sip.
- Don't offer him his bottle for "one last time" out of sheer desperation. If **you** persist, your child's normal thirst will take over and he will soon drink from a cup.

Does your child refuse anything but baby food or purees?

- Do consult with your family doctor to rule out any medical reasons that could prevent proper swallowing.
- Do offer small amounts of food you are reasonably sure your special child enjoys and cut it up into miniscule pieces.
- Do gradually increase the size of the pieces to bite size.
- Don't become alarmed if your child refuses to eat even the miniscule portions on his plate. Remain steadfast, rest assured he will not starve overnight. Eventually his desire for food will prompt him to taste.
- Do remember to praise your child enthusiastically when he does eat by saying "I like the way you are eating."

Is your special child a picky eater?

Does he develop "food fads" so that one month he will eat only cheese, the next only tuna and so on? Does your dining room turn into a battlefield whenever you try to get him to eat a more balanced diet?

- Don't give in! Calmly, and without making an issue out of it, don't offer your youngster his "food of the month." If possible, don't even have it in the house.
- Do serve small amounts of tasty food at your family's regular mealtimes.
- Do remove his plate WITHOUT COMMENT if your special child throws, plays with the food on his plate or refuses to eat.
- Don't become overwhelmed if your child tantrums. Remove him as calmly as possible from the table and place him out of earshot. Make sure that he cannot get into mischief elsewhere. Even though this behavior makes you angry, try not to lose control.

ABOUT THE AUTHORS

Linda Murphy, M.S., is the founder and for the past 15 years has been the director of a widely known, approved school for mentally handicapped children serving children ages 5-21 in Westchester County, NY, and surrounding areas. A lecturer, teacher and administrator, she is a foster parent and the parent of a handicapped child, too.

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• Don't offer food or drink **except water** until the next meal. Milk is very filling so make sure you only offer water.

• Don't become anxious or fearful that there will be a dramatic weight loss or a threat to your child's health.

• Don't become alarmed if your child misses a few meals before he begins to eat. You are bound to feel some anxiety and self-doubt, but if you don't back down your child's urge to eat will take over. Be persistent—the entire process should not take too long.

Does your special child fill up on snack food and refuse to eat at mealtimes?

• Do put a lock or gate on your kitchen door, or lock and tape your refrigerator closed.

• Do enlist the cooperation of other family members. Sit down with your family and ask them to refrain from snacking. Assure them that if everyone helps, the process will only take a short time.

• Do offer only small amounts of food at mealtime. Remove your child's plate without comment if he initially refuses to eat.

• Don't get discouraged with setbacks. If you find that your youngster has somehow managed to get into snack food, remove it without undue fuss at once—even if he tantrums.

• Do remain calm. Remember that you are in charge and that eventually your child's normal urge to eat will take over at mealtimes, not in-between.

Does your child have difficulty feeding himself?

• Do remember that a fork is easier to use than a spoon. If your child cannot use a fork at all, place the fork in his hand, then cover his hand with yours, making sure the pressure of your hand is helping him grip the fork. Put him through the motions of spearing a bite-size piece of food and carrying it to his mouth. Gradually stop your actions farther and farther from your child's mouth, until he is able to do it on his own.

• Don't become frustrated. This is a skill that takes constant practice.

• Don't feel like a failure if once in a while you are in a hurry and you find you must revert to spoonfeeding. Just set aside a small portion of each mealtime to practice.

• Do remember to compliment your child and praise him warmly for his attempts to feed himself.

Does your child constantly run away from the table at mealtimes?

Do you find yourself wondering if you should become a marathon runner yourself as you chase your child around and around trying to tempt him with a spoonful of his favorite food?

• Don't do it! If your child is unwilling to sit and eat at the table simply remove him, saying calmly but firmly "If you can't sit and eat with us you can't stay here. Goodbye!" Sometimes it pays to rehearse this phrase prior to the event.

• Do remove him to another part of the house, making sure he cannot hurt himself elsewhere.

• Do not offer him any food or snacks except water until the next meal. Chances are your child will test you and get up from the table again . . . and even again. Simply repeat the process, making sure you do not reward your child with undue attention.

• Do take into consideration that your special child has a sixth sense when it comes to sensing your anxiety over his eating habits. Even though he has been able to eat what he wants, where he wants, when he wants, you can regain control over your kitchen. Gradually, if you are firm yet calm, your child will realize you mean what you say and will behave in the same fashion as other family members.

Bedtime behavior

Often bedtime is a nightmare at worst, a difficult period at best. Your child's refusal to go to bed or stay in bed once there is a common problem that besets many special parents. It's only natural for you as a concerned parent to respond with drinks of water, pats and hugs and perhaps even outbursts of anger when your special child exhibits sleep disturbances. Sometimes problem nighttime behaviors occur because your child's misbehavior has been rewarded by adult attention. If your special child is able to garner any kind of attention from you throughout the night, it is enough to perpetuate bedtime misbehavior.

Do's and Don'ts

• Do provide a quiet environment for your child at night. Don't roughhouse just before bedtime. Give him time to shift gears.

• Do make sure your child is tired enough for bedtime by discontinuing afternoon naps.

• Do have a regular bedtime routine. Tell your child what comes next in the series of events leading up to bedtime. Try to do the same, pleasureable, unhurried things each evening. This could include TV, bath, a soothing story, bed.

• Do place your child in bed, gently but firmly, even if he protests. Turn the overhead light off. You may want to leave a small night light on. Explain to your child "this will help you to sleep." Close the door gently, but firmly, behind you.

• Don't respond to your child's outbursts of temper or pleadings. Remain firm even though this is probably one of the most difficult things you'll ever have to do.

• Do not reinforce your child's tantrum behavior by going into his bedroom to soothe, remonstrate or engage in conversation—remember, this is attention.

• Do make a mental note that this procedure invariably produces an **increase** in the tantrum behavior before the decrease occurs. This will be the most difficult period for you to endure. Many parents become fearful that great emotional harm will befall their child. They are beset with guilt and doubt especially if the nightly rages persist.

• Do be assured that this is not going to inflict permanent damage on your special child. WALK AWAY. Read a book, pour yourself a glass of wine. Rest assured that if you stick to your guns, your child's nightly tantrums will cease after a few nights.

• Don't lose heart if your youngster is one of those rare birds who has great persistence.

As harsh as this may seem, if you are consistent in ignoring the nighttime tantrums, they **will** decrease.

• Do enlist the cooperation of your family before you try this. Explain to everyone that they will have to endure a few weary days before this method takes effect.

Perhaps you have a slightly different nighttime problem. Your special child goes willingly to bed at bedtime but awakens in the middle of the night to raid the refrigerator or search and destroy.

• Do try putting a hook and eye on the outside of the bedroom door or turning the doorknob so it locks from the outside. Or install a simple alarm available at radio supply stores that is tripped when your child opens the door.

Remember that special children feel secure when they know what is expected of them. By being able to regulate your child's nighttime behavior you are bringing firm but loving stability to some of his inner confusion.

Embarrassing behavior in public

The world outside your door is not geared to making concessions to your special child. In order for him to live in this world he has got to learn to conform to the best of his abilities. Going out in public with your special child need not be a constant source of friction or embarrassment. He can, for instance, learn to tolerate the noises of the world—if given time and practice. Your special child cannot and should not be permitted to freely help himself to merchandise, to tantrum or otherwise misbehave in supermarkets, shops or elsewhere.

How did he get this way?

Often parents buy peace at any price. Paying for those unwanted items at the checkout counter that your child has pocketed is one way of avoiding a scene. While you might have established some ground rules for your normal children's behavior in public, you are not convinced your special child knows or understands acceptable behavior. Does your special child, for instance, tantrum in the supermarket at the precise moment you find yourself standing in line with $80 worth of groceries in your cart? This and other pitfalls can be avoided.

Do's and Don'ts

• Do start out with the conviction that your child is capable of acceptable behavior anywhere, anytime. By expecting good behavior, very often you will get it.

• Don't expect your special child to withstand lengthy shopping expeditions **unless** he has been given plenty of prior training. Often your child's misbehavior or hyperactivity in stores is due to his inability to screen out excess stimuli—canned music, glaring lights, large crowds, overwhelming displays, noises, lengthy waits. You might loathe shopping for the very same reasons and perhaps not know why.

Begin desensitizing your child by doing the following:

TEACHER TALK:
HELPING YOUR CHILD LEARN SIZE DISCRIMINATION

Boxes of dried beans found on the shelves of your supermarket are wonderful teaching tools for learning big and small. Buy several boxes in various sizes and colors and have your child sort them. Start with only two sizes. Use large kidney beans and small split peas, for instance, to teach him the concept of large and small. Keep the sessions short. Make a game out of it and keep rewarding your child with verbal praise or a sticker when he sorts the sizes correctly.

- Select a store with a familiar layout so that you can enter and leave quickly with just a few purchases.
- Select a time when you know the store is not busy.
- When you enter the store, be sure you are holding on to your child's hand firmly. If he is small enough, place him in a shopping cart, if available. If he protests, ignore this behavior. You can console yourself knowing that you have planned ahead of time so you can make a speedy exit. Make your purchases as quickly as possible.
- Do praise or reward your youngster with a tangible treat such as a tidbit of food, but only if your child **is** exhibiting good behavior.
- Don't get concerned that you are bribing your child; psychologists call what you have done "positive reinforcement."
- Don't become discouraged if your child misbehaves. Continue to be calm, yet firm. If necessary, hold his hands down at his sides, instructing him to "keep hands at sides." This makes more sense to a handicapped child than "don't touch." By the same token "close your mouth," or "lips together," is a more effective concrete instruction than "stop crying" and is easier to follow.
- Do gradually increase the allotted time in stores, malls, markets and restaurants.
- Do plan ahead—if you are confused or indecisive, or waste time making purchases, your child will pick up on this and become restless.
- Do maintain eye contact as much as possible when you are with your special child in public places. Reassure him that all is well by speaking to him in low tones. Reward him with verbal praise or food tidbits as you quickly and efficiently make your purchases.
- Do permit him to take a favorite toy or other small object that will amuse or reassure him in confusing environments.
- Don't make idle threats. If you tell him beforehand that the consequence of his misbehavior is leaving the store or restaurant and going home to bed, do it—even if this means abandoning your shopping cart or leaving the restaurant with food untouched. Remember to practice with just a few items in your shopping cart and just one item of food in a fast food restaurant!

These practical pointers take time and planning on your part. They are well worth it, however, if your child senses that you are the one in charge and acts accordingly. By gradually increasing the time spent in public, by rewarding your child's good behavior with eye contact, verbal praise and tangible treats, you will eventually discover how pleasurable it is to have him along as you visit restaurants, shops and other places of interest.

Always remember that the key to changing your special child's behavior is not only discipline, but reacting to him in a positive manner when he is good. Make a mental note to observe your child throughout his day and seek opportunities to praise him and reward him when you note that he has done something appropriate, however small.

Your ability to take charge plus your positive attitude will increase your special child's self-esteem and enhance his ability to control himself.

Psychologist's Corner: "WHY ME?"

by George Popper, Ph.D.

IN FUTURE ISSUES LEARN ABOUT:

- Those Psychological Tests: What Do They Mean?
- Speech: Ways to Encourage Your Child's Ability to Communicate
- Your Child and School: Getting Your Child and Yourself Through The Special Education Maze
- Behavior Modification: Encourage Positive Behavior With Our Pull-Out Star Chart

Plus much, much more!

"How's my baby? Is everything O.K.?" These are the questions to which every parent hopes to hear: "Your baby is fine." But for some parents, the answer is very different. "I'm afraid there's a problem. There is something wrong with your child." It's hard to imagine words with a more devastating impact than those. Perhaps having your doctor tell you you're about to die would be easier to take. "There must be some mistake! How can you be sure?" You hope against hope and pray that there's been an error. After all, doctors and hospitals have made mistakes before. There's never been anything like this in your family so how could this be true? But deep in your heart you know that it is. Feeling angry, hurt and afraid, most parents just do not know what to do. What will their family and friends say? How will they be able to care for an "imperfect" child? Should they place their child immediately in an institution lest they become too attached? Not many years ago, well-meaning doctors automatically told parents that it was best they never saw their handicapped child and that they should have the child placed in an institution where "proper" care could be given.

The first step is to come to terms with the fact that you are only human and your feelings of despair are normal and expected. Even denial is normal and necessary because it can act as a buffer to lessen the impact of a traumatic event. But to deny your feelings beyond a reasonable time is destructive. It's important to remember that your feelings of anger and hurt will eventually pass as long as you're willing to face them. There are some who feel the need to use drugs or alcohol to lessen the pain. Not only doesn't it work, it makes things much worse. There are those who act as though they were superhuman and able to deal with any adversity on their own. The truth is you're not alone and you are going to need help both now and later on. Seeking the support of others does not mean that you are weak or have lost your independence. Developing a support system and using it to its fullest is necessary for your child, yourself and the well being of your family. Don't panic! Give yourself time to think. Decisions that are made when we are frightened or under stress are often regretted later. Remember, allow yourself to feel even if the feelings hurt, deal with them openly and honestly, don't go it alone and don't make decisions out of fear or under pressure.

After the hurt and confusion, reality settles in. Most parents eventually discover that handicapped children need parents too and that special children can sometimes make us special parents. One well-known opera star (and parent of a special child) said that the change for her came when she stopped saying "why me?" and started saying "why him?"

When the shock and pain are finally gone, we learn that self-pity and guilt serve no useful purpose other than to make us feel miserable. To be an effective, loving parent you have to go beyond those emotions. And once you do, you've won . . . and so has your child.

THE READER ASKS . . .

QUESTIONS AND ANSWERS

We invite inquiries or hints from our readers. If you have a question, a problem or comment about any aspect of parenting special children, write to:

Special Parent/Special Child
Lindell Press, Inc.
P.O. Box 462
South Salem, NY 10590

Q. I have just been told that my five-and-a-half year old daughter is moderately retarded. Exactly what does this mean? What will her future be like?

A. The term "moderate mental retardation" implies that your daughter has not acquired many of the skills that would be expected of a child her age. For example, moderately retarded children often have language difficulties which show up in their inability to always understand what is said to them as well as inability to clearly express things that are on their mind. Number skills such as simple counting are also sometimes deficient. Some moderately retarded children have difficulty with motor coordination and seem to be more awkward than their peers. They also seem to have difficulty making friends or playing with children their own age. Overall, a moderately retarded youngster functions on the level of a much younger child. Often, retarded children have "splinter" skills, or unusual abilities in one narrow area which can mislead one into thinking they have more ability than they really do. Intelligence tests, from which your daughter's IQ score was derived, can pinpoint some of her strengths and weaknesses. Her future depends more on the kind of training and special education she receives today so it would be unwise to make too many predictions.

Q. My son, age nine, can't sit still on the school bus. He gets out of his seat belt and has so many bus conduct reports I'm afraid they will suspend him. My husband and I will be late to work if we have to drive him ourselves. Help!

A. Suggest to the school bus driver that your son carry a "bus book" back and forth. Get a notebook and divide each page as illustrated. Ask the bus driver or monitor to give your child a happy face or unhappy face, depending on his behavior. Make sure your son understands he will receive a special treat **every** day for a happy face and no treat or loss of TV or other privileges if he misbehaves even once. Reward him with extras or a "treat of the week" for good behavior all week. Don't be overwhelmed by lapses. By consistently rewarding your son's good behavior, his bus conduct should improve.

Week of: March 5th	AM	PM
Monday	☺	☺
Tuesday		
Wednesday		
Thursday		
Friday		

Future issues of SPECIAL PARENT/ SPECIAL CHILD will explore in detail psychological tests and their importance, plus your child and school.

Illustrations by Leah Spring

Special Parent ★Special Child

Practical pointers for parenting handicapped children

VOL. 1, NO. 3 MAY/JUNE 1985

SPEECH: Helping your child communicate

In this issue you will be given pointers on how to enhance your special child's ability to speak and communicate.

Many special children have speech and communication problems. Quite often they don't begin with the one or two word utterances that develop into normal sentences. Sometimes there is a delay in speaking at all. Even when speech occurs, it is often garbled or meaningless. Many special youngsters speak too loudly, blurt things out of context, or talk in circles, never quite able to communicate exactly what they want to say.

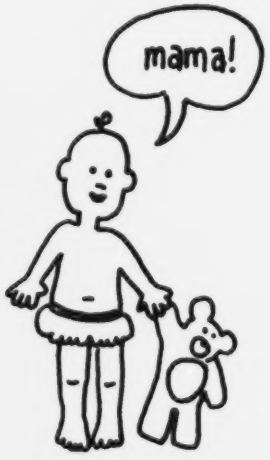
When to get help

Don't delay. It's important to know that your special child will not "outgrow" speech difficulties. If you have any concerns that your child is not speaking the way you think he should, don't panic, but don't ignore it in hopes that time and maturation will take care of things. Before you decide to get help it's always a good idea to be able to tell if your child's language milestones are within the normal range.

Checklist of normal speech: what to look for

By age six months infants have begun to babble and say syllables such as "dah" and "mah". Infants at this stage coo, make noises, and find pleasure in the sounds they make. They turn their heads towards noises such as the sound of the door opening.

At one year your child should be able to imitate all sounds, point, gesture and say several simple one-syllable words such as "bye", "car". He should be able to



imitate familiar words such as "milk" and be able to point to "eyes" on command. Many year olds can even put two words together such as "bye, bye" or "go, car". What is most important is that your child is beginning to associate words with their meanings. This is essential in language development.

By age two children usually can form two and three word sentences such as "go bye, bye" or "go car, car". A two year old can point to all his body parts and may even begin to use pronouns such as "me" or "mine". Two year olds are inquisitive, they point to pictures and ask "what's that"?

By age three speech should have developed to the point where your child can converse in simple sentences. His understanding of words and his language concepts have developed so that he understands the meaning of "Don't touch, it's hot", for example. He can give his first and last name, can count numbers by rote and recite familiar nursery rhymes.

By age four language skills have developed almost miraculously. Many four year olds chatter incessantly, keeping up a non-stop barrage of "why" and "how". Four year olds are able to reason things out and can answer such questions as "what do you do when you're thirsty?"

By kindergarten most children understand the concept of colors, numbers to four, can count by rote, know sizes and shapes, and the more complicated relational concepts of next to, in back of, etc.

By age seven language has developed by leaps and bounds. The average vocabulary of a normal seven year old consists of approximately 2500 words.

ABOUT THE AUTHORS

Linda Murphy, M.S., is the founder and for the past 15 years has been the director of a widely known, approved school for mentally handicapped children serving children ages 5-21 in Westchester County, NY, and surrounding areas. A lecturer, teacher and administrator, she is a foster parent and the parent of a handicapped child, too.

Suzanne Della Corte, M.S., for 15 years co-director of the school, is responsible for curricula, staff development and supervision. She is author of numerous research projects in the field and has edited psychology textbooks for a leading New York publisher.

If you suspect a problem: getting help

If you feel that your child's language milestones are not within the normal range, don't hesitate to consult your pediatrician. Even if he advises to "wait, it's too soon to tell," insist he refer you to the nearest Speech and Hearing Center for a complete evaluation. It's essential to assess your child's ability not only to hear but to understand language. If your doctor cannot refer you, look in your telephone Yellow Pages under Speech and Hearing. Even if your child is not of school age, the local school nearest you might be able to refer you to a speech center or to a speech pathologist.

ABOUT SPECIAL PARENT/SPECIAL CHILD:

Special Parent/Special Child is a bi-monthly newsletter published by Lindell Press, Inc., P.O. Box 462, South Salem, New York 10590. Special Parent/Special Child is designed to promote effective family functioning between parent and special child. Bylined articles do not necessarily reflect the publisher's viewpoint. Annual subscription rate is $15.00 per year. Send check to Special Parent/Special Child at above address. Reprints are available at $3.00 per issue. Copyright ©1985. All rights reserved.

The Speech Evaluation: what to expect, what to look for

A good speech and hearing evaluation should include:

Social History. You will be asked to provide information regarding your family's health history, your pregnancy and your special child's individual health history.

Audiogram. This special hearing test, administered by an audiologist, determines if your child's hearing is within the normal range.

Speech and Language Assessment. Speech is your child's ability to form sounds and then words. **Language**, on the other hand, is the ability to associate what the words mean and then be able to use those words to form concepts, make generalizations and to communicate needs, thoughts, wants. If we think of speech as sound, then language is order, sequence, and meaning.

The **Speech Pathologist** (also known as Speech Therapist) will listen carefully to your child during the assessment and will evaluate your youngster's ability to use words in combination, form phrases and sentences, ask questions, make comments or share previous experiences.

During the **Language Sample** which takes place in a relaxed setting, the speech pathologist will observe how your child plays, specifically if he uses toys appropriately and what he does with doll-like figures. More than likely, your child will also be given some tests that will evaluate his language development in relation to his chronological age.

Oral Peripheral Examination is done by the speech pathologist to determine if there are any structural defects in your child's palate, mouth, tongue, jaw or teeth that might interfere with speech. Any irregularities should be checked out by an ear, nose, and throat doctor.

Neurological Examination. Sometimes, although not often, the speech pathologist will suspect that a brain dysfunction underlies your child's speech delay or problem. If that is the case, then a recommendation will be made for you to consult a neurologist.

Speech Conference. The next step is for you and the speech pathologist to sit down and discuss your child's overall speech and language development, and the results of all the samples and tests.

Although speech therapy sessions with the specialist are often indicated, there are many ways parents can help their special child at home.

Words you should know

- **Receptive Language** - Ability to understand what is said.
- **Expressive Language** - Ability to speak outloud words and sentences that communicate needs, wants, thoughts to others.
- **Articulation** - Ability to form speech sounds correctly.
- **Articulation Defect** - Difficulty in forming speech sounds correctly.
- **Aphasia** - Difficulty in understanding and using language.
- **Receptive Aphasia** - Difficulty in understanding spoken words, so that although the sounds are heard, the brain is unable to translate the sounds into words that make sense.
- **Expressive Aphasia** - Difficulty in speaking, so although what is said might be understood, the brain is unable to translate the thoughts into spoken responses.
- **Speech Delay** - A lag in the development of spoken language. For example, using one word instead of whole thoughts.
- **Speech Therapy** - An individualized program designed by a licensed professional using games, supervised play and conversation which will aid in the acquisition of language.

What you can do to help

Remember that children are not "taught" speech, they acquire language within the course of the day, with you at home, doing normal, everyday things. You can enhance your special child's ability to communicate if you follow some easy pointers.

Do's and Don'ts

Do give your child a reason to talk. It is important for your child to have a reason to talk. If you anticipate his every wish and need, he will have no reason to talk. You must give him a reason to speak. You may say **gently** when he points and gestures, "I don't understand what you want." Or, still more simply, "What?" Do not overdo this. Remember you have been taking care of his unspoken needs for years. Never, never, never punish a child who continues to point. Praise every effort he makes instead.

Do remember to talk to your child. Your child will learn to use words by hearing them over and over. Talk to him constantly. Talk to him about his clothes as he dresses, naming each item; name his food as he eats; identify the parts of his body as he bathes. Speak clearly and slowly. Always be sure he knows you are talking to him. If you speak to him from across a room, he may not know you are speaking to him or may not even realize you are speaking. Bend down to his eye level if necessary. Never use extra words. Large sentences will confuse him, and some children will only hear one or two words in a six word sentence. Instead of saying, "Now we will go inside and have lunch," say "Time for lunch."

Many parents say "He understands everything I tell him but he still won't talk!" All children understand before they talk. Although it's frustrating, keep on talking, using a calm tone of voice.

Don't make a fuss. When your child begins to speak, don't become overexcited. You may have waited a long time for a single word but **do not** make him repeat it over and over for each person he comes in contact with. He may become overwhelmed and frightened and refuse to speak again. If this happens, don't push. Be patient. Gradually he will begin again. When he does begin to talk, listen to what he has to say quietly and with interest.

Do give words extra meaning. You can help by making words meaningful to your child. The word "dog", for example, will mean nothing to your child unless you have him touch, pet, feed a dog, while you say the word dog to him. The more examples you can give your child, the more readily he will grasp words and their meanings.

Do continue to read and sing to your child. Learning to listen is a large part of learning to talk. Read to him often. Find books which tell stories about things he is familiar with, things he has seen and done. Sometimes it is very hard to find short, simple books. You might prefer to make your own by pasting large pictures on colored paper held together with colored yarn. Keep your story short and simple. Remember, his attention span is short. Use as few words as possible.

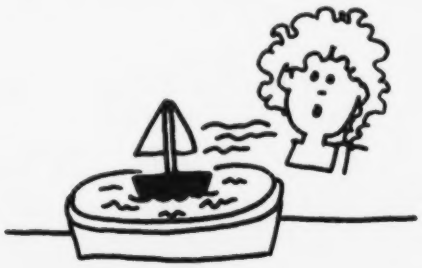
Sing to your child. Many children sing before they speak. Buy him records—short children's records—so he can listen to them frequently.

Don't get frustrated. It can be very frustrating to go on talking to an unresponsive child day after day, but don't give up. Try to relax, be very patient. Don't get upset or tense; he will be tense and frustrated if you show that you are. Talk, laugh, and sing to

him, talk, laugh, and sing . . . .

If your child speaks but does not do so correctly, don't be upset. Do not correct his every effort. Pronounce the word correctly for him. If he will repeat it, good. If he will not, do not force him.

Do try these activities. There are a few exercises which will help him to speak clearer and better. Make a game of them. Have him blow, feathers to start with. Then blow bubbles through a straw or sail a boat across a pan of water. You can also have him blow on a horn, or whistle. Let him stand in front of a mirror and make faces, show him how to stick out his tongue at himself. Laugh and make a big game of it. In order to teach him to put his tongue on the roof of his mouth for "th" sounds, etc., put some honey on his top lip and let him lick it off. Give him food that



needs lots of chewing—celery, carrots, apples, etc. All of these exercises will strengthen his facial muscles and aid tongue and mouth movements.

Do help the child who rambles on. Try using photographs of actual events and have your child sequence what event comes first, next and so on. Figuring things out in order is a complex skill, so plan on doing this quite often.

Remember, always make it a game or you and your child will both be frustrated.

Psychologist's Corner: MANAGING STRESS

by George Popper, Ph.D.

We've been hearing a great deal about stress, how it relates to a family with a handicapped child, and what can be done to alleviate it. First, it is important to understand what stress is and what it can do to us physically and mentally.

Whenever we are faced with a situation that requires us to respond in some way, we are under stress. Getting up in the morning, planning a vacation, and getting a divorce are all examples of stress situations. Not all of the situations are necessarily bad, but they are all potentially quite stressful. Usually, we are able to adapt to changes and to events without difficulty. But when stress becomes overwhelming and we can no longer adapt, we are said to be under a condition of "stress".

Having a handicapped child has a high potential for creating an enormous amount of stress in a family. How can you tell when you are under stress? Often, the symptoms are not as obvious as one might imagine. Sleep disturbance, eating and weight problems, infections, allergies, rashes, and other "physical" ailments are frequently thought of as medical problems but often can be attributed to stress. Emotional symptoms could include anything from mild depression and anxiety to a complete mental breakdown. No one is immune. Given enough stress, for a long enough period of time, anyone will suffer. Knowing all of this, what can you as the parent of a special child do?

When faced with potentially stress-inducing situations, ask yourself three questions:

IN FUTURE ISSUES LEARN ABOUT:

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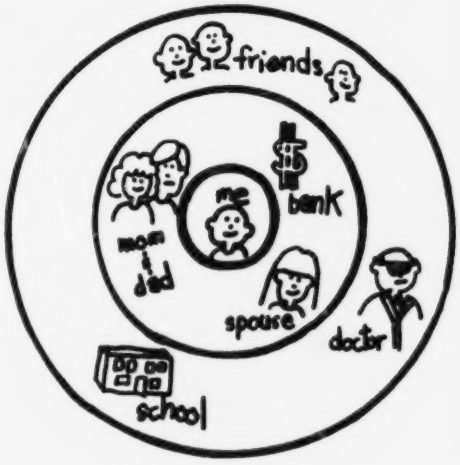
Plus much, much more!

1. Is there anything I can do about this situation right now? More times than not, the answer is no. The stress occurs when we believe we must do something when in fact we can do nothing. For example, you're on your way to work and you are stuck in a traffic jam. If you wish, you can become hysterically angry, but the traffic will not move any faster. Understanding that there are some situations over which you have no control can reduce unnecessary stress.

2. Are there things that I can do, and, if so, what are they? What strategies can I develop to effectively deal with this situation? In order to answer this question, you might find it helpful to do some advance planning. Draw a series of three or four concentric circles (like a target) and label the middle circle "you". In the outer circles, put down the names of people (family members, spouse, friends, professionals, etc.), agencies, assets and other resources that are available to you in the event of a crisis. Put them down in approximate order of importance. In this way you can better visualize where you can go for help when you need it. Many times, people are victimized by stress because of inadequate planning. Developing a network of backup support provides parents and children with the kind of help that would have been unavailable had plans not been made. Forestalling a crisis situation by planning ahead is one of the best ways to prevent being overwhelmed.

3. What is the worst thing that could happen if everything that can go wrong does? Looking at a situation realistically and evaluating all possible outcomes—from the improbable to the likely—allows you to develop methods for dealing with it. More often than not, looking at a "worst possible" situation tends to be more reassuring than frightening, since even the very worst outcomes are not always that drastic.

NEXT ISSUE will deal with more ways you can handle stress.



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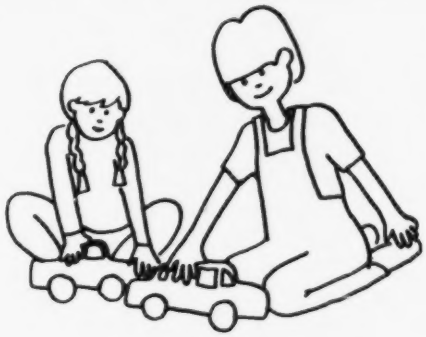
Q. What do I tell my child, age 11, when he comes home crying that the kids on the block call him "retard"? How can I explain to him that he is different without hurting him?

A. Children can be unthinkingly cruel, especially when they don't understand. Try telling your son this story as an explanation. "You know that cars have different size



engines. Some cars have 8 cylinder engines and some have 4 cylinders. The 8 cylinder engine goes faster. The 4 cylinder car is a fine car but it is slower and takes a little longer to get where it's going. But both cars get to where they want to go!" Explain to your son that he is like the 4 cylinder car—even though he goes slower, he **does** get there. It might be helpful to have your son attend recreational programs for special children or to participate in activities such as Special Olympics where he can compete with peers at his own level.

Q. What do I do about my son, age 14, who is always touching his private parts? I keep telling him to stop but after a while he starts up again. I am so embarrassed that I hate going out in public with him. Can you help?

A. Your son's growing sexuality cannot be turned off, but it can be channelled appropriately. You can tell your son that you understand that it feels good to touch yourself but that it cannot be done outside of his own bedroom. Tell him touching himself is done at home, and that it is bad manners to touch himself **in front of others.** If the sexual behavior occurs in public, remind him each time by first getting eye contact. Then instruct him firmly but gently "Keep your hands at your sides. Wait until you are home and can go up to your room by yourself." Gradually, your son can be taught appropriate sexual behavior that will not embarrass you or others.

Future issues of SPECIAL PARENT/ SPECIAL CHILD will be devoted to Sex Education for Special Children.

Illustrations by Leah Spring

NEXT ISSUE: School's Out—Time to Play

Special Parent ★Special Child

Practical pointers for parenting handicapped children

VOL. 1, NO. 4 JULY/AUGUST 1985

SCHOOL'S OUT! IT'S TIME TO PLAY

Many parents and teachers do not consider playtime as important as academic achievement. They couldn't be more wrong. In this issue we will explore the importance of play in your special child's development and how you can make this summer a productive, relaxed time for you and your child **while playing.**

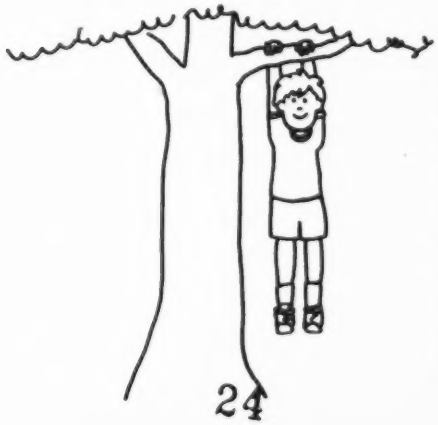
Why play?

Learning through play is one of life's most natural experiences. In normal children play both nurtures and teaches. Play, in the natural course of events, enhances feelings of self-reliance, self-esteem, spontaneity and creativity; it gives children the chance to become one of the gang and to figure out how things work. Through play children exercise their intelligence, their emotions and their muscles!

One of the saddest problems for many special children is their inability to engage in play. Moreover, their handicap becomes magnified by their emotional reactions when they sense their limitations in play situations.

How did he get this way?

Perhaps your child has physical or emotional handicaps that limit his interactions with others. Maybe his developmental delays or excitability or short attention span limit his ability to sustain many activities, even play.



Perhaps your child's need for more supervision makes you reluctant to allow him the freedom of playing with neighborhood children. Or perhaps your child does not have the language skills that permit him to join.

Whatever the reason, it's hard not to feel guilty when you realize that your special child lacks the necessary play skills and, consequently, avoids or is avoided by other children. However, it's never too late . . . many of the skills that develop through spontaneous play in normal children can be "taught" to your special child this summer through relaxed leisure time activities.

Do's and Don'ts

ABOUT THE AUTHORS

Linda Murphy, M.S., is the founder and for the past 15 years has been the director of a widely known, approved school for mentally handicapped children serving children ages 5-21 in Westchester County, NY, and surrounding areas. A lecturer, teacher and administrator, she is a foster parent and the parent of a handicapped child, too.

Suzanne Della Corte, M.S., for 15 years co-director of the school, is responsible for curricula, staff development and supervision. She is author of numerous research projects in the field and has edited psychology textbooks for a leading New York publisher.

• **DO start each play activity with something your child has already mastered.** It will give your youngster that extra bit of confidence to go on to something more challenging.

• **DON'T choose activities that make unfair demands on your child's capabilities.** Remember that special children more than anyone need to feel the sweet reward of success.

• **DO quit while you're ahead.** Anytime you engage in a play or leisure time activity with your child **stop** while you are both still fresh and eager. Remember—this is **play** and your time together should be a pleasure and not a chore.

• **DON'T feel it is necessary to buy elaborate or costly equipment for your youngster,** or even to rearrange your family's schedule. The object of all "guided" play is to instill in your special child feelings of competency and self-worth, and this is best done if play activities are interwoven into the natural context of family life.

The following indoor and outdoor games and activities are intended only as a guide. Each family should choose the ones they prefer, or, even better, create their own imaginative play environment.

Outdoor play

• **DO start a hobby** you can enjoy together such as a shell collection or leaves, flowers, rocks—anything that is easy to collect within your own environment. Talk to your special child about the objects in the collections, especially the difference in size, shape, color.

• **GO for a walk together.** As elementary as this sounds, taking a walk is an excellent learning-while-playing activity. Your own childhood pavement games of "step on a crack," for example, can take on new meaning for your special child as many sidewalk games actually help coordination.

• **MAKE a map** of the neighborhood as you take your walk. Translating a two-dimensional map into three dimensions is not only fun but is an important directionality skill.

Turn the everyday into an excursion.

• **A treasure hunt** in your own backyard or in a park is an activity the whole family can enjoy. This type of play also encourages visual memory. If your special child hates to compete and fears failure, perhaps he can be encouraged to participate in a more relaxed setting. Give him extra clues if necessary and keep things low-key.

• **A trip to the post office** can become an experience for your special child especially if he is given an opportunity to pay for the stamp and mail the letter.

ABOUT SPECIAL PARENT/SPECIAL CHILD:

Special Parent/Special Child is a bi-monthly newsletter published by Lindell Press, Inc., P.O. Box 462, South Salem, New York 10590. Special Parent/Special Child is designed to promote effective family functioning between parent and special child. Bylined articles do not necessarily reflect the publisher's viewpoint. Annual subscription rate is $15.00 per year. Send check to Special Parent/Special Child at above address. Reprints are available at $3.00 per issue. Copyright ©1985. All rights reserved.

• **PLAY ball.** This is not as simple as it sounds since so many special children have hand-eye or motor (body) coordination difficulties. If your youngster has trouble catching a ball, try using articles that move through the air slowly, such as rolled-up articles of clothing or a small pillow. Many children need to clutch before they can catch. As your child improves you can gradually switch to sponge-type balls and finally, regular balls. Using a balloon instead of a birdie while playing badminton is fun, too.

• **TEACH him the rules of the game.** It is important for your child to learn the rules of various games as much as he is able. Even if your child lacks the ability to compete, he can gain pleasure from sports activities if he knows how to keep score. If he also understands the rudiments, chances are he will not become bored or restless when the family attends ball games. Keep your child up-to-date on the names of sports heroes. In that way he won't feel so much of an outsider.

Indoor activities: games people play

• **PLAYING board games is important.** Start with some simple ones such as Candyland® , Chutes and Ladders® , Bingo® . These games are fun, easy to master, encourage turn taking, and, what is more important, how to **win or lose** with good sportsmanlike behavior.

Always encourage your special child to keep score.

• **PLAYING simple card games** is a valuable skill. Start with easy to understand games such as "War," or "Go Fish." Through practice your special child can excel and even win. Learning how to shuffle and handle cards is excellent for your child's manual dexterity. The ability to discriminate cards and their value is really a complicated math skill. Some children with physical handicaps might make use of a card holder.

• **MAKE T.V. time productive.** Parents of all children, not only special children, often feel guilty about the amount of time spent watching T.V. Make it a point to choose at least one T.V. program you can watch together. Ask questions about the story and the characters so that the whole family can share in some give and take.

• **BUY an old-fashioned hand-turned ice-cream-maker** and make ice cream for everyone. Turning the crank strengthens muscles and, if more than one person is involved, encourages turntaking and sharing.

• **READ aloud to your child,** every day if possible. You could begin with a short book borrowed from the library or you could read a chapter each day from a longer book. Predictability and the same consistent activity in a sometimes unstructured summer is very reassuring to a special child.

Why not a pet?

Taking care of a new pet is generally easier in the summer when families have more leisure time. Pets are invaluable surrogates to special children who are often unable to sustain friendships with real playmates. A dog, for instance, can serve as a special child's confidant, join in his play and offer him comfort and unconditional love in times of loneliness. If you do decide to get a pet this summer, make sure your youngster shares in the responsibility of the animal's care and feeding.

What about camp?

Handicapped children, above all others, need to feel they are successful. Parents should be aware that placing their special child in a competitive camp environment beyond his natural capabilities leads to withdrawal and provokes despair. For that reason alone, it is vital that parents choose a day or sleep-away camp with their special child's unique needs in mind.

Practical pointers for choosing a summer camp

• Visit the setting if possible. Are the living quarters safe? Comfortable? Roughing it is fine, but are minimum safety requirements met? Is there adequate indoor and outdoor equipment? A waterfront safety program?

• Talk to the camp director—by phone if the distance is too far for a personal interview. Are you comfortable with his philosophy and goals for his campers? Are his attitudes towards discipline and structure, for instance, consistent with yours?

• Talk to the parents of children who have attended the camp. Ask them if they were satisfied with the level of care, the supervision, the kind and quality of activities.

• What are the ages and qualifications of the staff? In special camps there should be a higher staff-camper ratio. The supervisory staff should be highly experienced and the counselors should have some kind of training in education or allied fields.

• Does the camp's schedule lend itself to consistent daily activities? Remember that special children do best in predictable, structured environments.

• Are parent visiting days regularly scheduled?

• Most important, is there a balanced mix between affection and discipline?

If you are satisfied that the camp can offer your child a secure, happy recreational experience, then by all means relax, knowing that a summer spent apart will be not only productive but allow you to face each other with a refreshed outlook.

Creativity and your special child

by Dvora Krueger-Sertillange, Ph. D., ATR

Creativity is the part of human activity that gives richness, pleasure and, indeed, joy to life.

Creative people are described as those who see things from different perspectives. They can see relationships of objects and processes in new and perhaps unanticipated ways never thought of before.

Artists, painters and musicians are not the only people functioning creatively—Thomas Edison and Albert Einstein, for example, possessed superbly creative minds. They were able to play with ideas and juxtapose elements of problems in ways that created new theories. They were not tied or limited to the existing conventions of human thought. They had not forgotten to "play."

Child's play, which as parents we may dismiss as unimportant or trivial, is really the cornerstone of learning for children. The more exposure children have to problem-solving activities in their play, the more they learn about causes and consequences in their "real" world.

As parents of exceptional children with conceptual or neurological handicaps, it is most important to establish opportunities for your child's explorations in **expressive** play, which is best represented by the creative arts. While art production and play are different to be sure, creative activities parallel play.

In creative arts there are endless possibilities for experimenting and making connections between cause and effect.

When structuring art experiences to do with your special child at home, here are some suggestions:

- Be less concerned with the end product and more with the sensory effects of the processes.
- Do not compare your special child's perhaps crude product with other children's.
- Do not judge—simply accept the art work with a hug and praise.
- Try not to be too literal. If you inquire about the art work and its meaning, just ask: "Can you tell me about this picture?"
- Let your child roam freely to explore the medium you have provided. It may be difficult for your child to organize the content of a picture or clay object conceptually so that it has a symbolic significance.
- Remember that you can be an excellent model for your special child. Join him in the art experiences fully and completely. If you do this, your child will associate creative activities with togetherness and closeness. Sometimes what we cannot say in words can be eloquently expressed in one simple, even primitive, drawn image. By participating in this creative-play, you too may find your old sense of play. The "work" you do with your child does not have to be

TOYS FOR SPECIAL CHILDREN

Toys designed for kids-who-can't-play-with-toys is the specialty of Steven Kanor, Ph. D., Rehabilitation Engineer. Dr. Kanor modifies commonly available commercial toys to meet the needs of handicapped children. For information or catalogues, write to:

Steven Kanor, Ph. D.
8 Main Street
Hastings-on-Hudson, New York 10706

TOY LIBRARY

The concept of the Toy Library is that toys are not just for playing. Toys enhance coordination and promote learning. Toys stimulate—they increase awareness, teach causal relationships and as children learn to manipulate a toy, they are more able to control their environment. For more information about a complete library of available toys plus books on the importance of play, write:

U.S.A. Toy Library Association
5940 West Touhy Avenue
Chicago, Illinois 60048

joyless and stressful—art can help you paint a rainbow together.

Here are some suggestions for activities you can share with your special child at home:

1. **Tempera painting** on wet paper. Get large heavy drawing paper—manila paper will do. Permit and encourage your child to work large and freely with paints. Secure paper to a table with tape and invest in a large, long-handled brush.

2. **Spray shaving foam** from an aerosol can onto a formica surface in the kitchen and sprinkle the foam with a few drops of food coloring. Tape a working rectangle to the surface around the foam—the foam stays within these boundaries. Your child can pull and draw with the foam as with finger-painting. Images can be erased and repeated many times.

3. **Figure tracings.** Tape brown paper from a large roll to the floor. Have your child lie down on the paper and trace around his body with a bright crayon. Next, have your child do the tracing of your body, perhaps with help from another family member. Fill in the silhouettes of your body shapes with paint or create a collage by selecting and cutting out pictures from magazines of food, people's faces, cars, objects, toys. Let your child choose the images he wants or likes best. Glue these down within the outline of the traced figure. This project stimulates verbalization, as do those previously described.

For more information about art activities for your special child, the following literature is available by writing to the publisher, or ordering from a bookstore. They may also be available at a public or special school library.

Schmidt, A.—**Craft Projects for Slow Learners** (John Day, 1968).

Uhlin, Donald—**Art for Exceptional Children** (Wm. O. Brown, 1973).

Psychologist's Corner: SUMMER STRESS

by George Popper, Ph.D.

IN FUTURE ISSUES LEARN ABOUT:

- Those Psychological Tests: What Do They Mean?
- Your Child and School: Getting Your Child and Yourself Through The Special Education Maze
- Behavior Modification: Encourage Positive Behavior With Our Pull-Out Star Chart

Plus much, much more!

Summer is here, school is out and the children are home. For parents of special children, this can be a stressful time. However, there are steps that can be taken to relieve the potential stress and make this time of year enjoyable for all.

1. Plan ahead. Needless to say, having planned activities for your children such as camp or another day program goes a long way toward relieving stress. If you are unsure of what's available, your county Association of Retarded Children or Parks and Recreation Department can be of help. Recommendations from other parents or teachers will be useful. As with many of our plans, things can go wrong, so it is helpful to have a backup in case your primary plans fail.

Don't make plans that are too complicated or cumbersome—the simpler the better. To the extent possible, everyone should participate in the planning. This can avoid ill will later on.

2. Take time for yourself. We all need a rest and we all need an opportunity to get away. Some parents feel guilty if their plans don't include all their children all the time. The guilt is undeserved, however. Time away from your children allows you to unwind and, in the long run, to be more effective as parents. That is not to say that you shouldn't spend time together as a family—you should. Wherever you go and whatever you do, however, should take into consideration the limitations of your special child. This would include physical as well as behavioral limitations. Remember, the kinds of activities parents enjoy are often different from the activities their children enjoy. Plan accordingly.

3. What about your other children? Summer is their vacation time, too. Their needs are different from your special child's and they should be taken into account. It is sometimes unfair to ask them to become baby sitters when they want to be with their friends. Or, if your whole family loves to go camping for instance, and your special child can't, by all means go on the camping trip. Leave your special child with a baby sitter. Perhaps respite care is available in your area. **Do not feel guilty.**

Remember, summer is a time when we can regain our strength. You've worked hard during the year and both you and your family are entitled to the rest.

THE READER ASKS . . .

There have been so many queries directly related to speech that the editors have asked guest columnist **Annebelle Scavuzzo, M.S.**, licensed speech-language pathologist of the Department of Communication Disorders, Boston University, to reply to the most frequently asked questions about speech and language.

Q. Why did my pediatrician wait so long to refer me for an evaluation of my child's speech and language problem?

A. Pediatricians see many children with highly variable growth rates in all developmental areas. The majority of children they see do "catch up." Moreover, because speech and language are considered nonmedical, pediatricians may adopt a "wait and see" attitude, not fully realizing that children generally acquire much of their native language between infancy and the early preschool years. I wish children would be referred from 18 to 24 months.

QUESTIONS AND ANSWERS

We invite inquiries or hints from our readers. If you have a question, a problem or comment about any aspect of parenting special children, write to:

Special Parent/Special Child
Lindell Press, Inc.
P.O. Box 462
South Salem, NY 10590

Q. When my child ignores or refuses my requests, is it because she does not understand me or because she is misbehaving?

A. When a child repeatedly ignores or refuses parental requests, parents should question hearing ability, the level of language complexity used in the request and the child's general ability to follow through on the request before assuming a discipline problem. Comprehension, attention and hearing problems should be ruled out first.

Q. Why is my three year old child repeating words and phrases, struggling to talk and, seemingly, "stuttering?"

A. Some children, particularly between 30 and 36 months, experience a period of normal nonfluency or interruption in their speech typically characterized by word and phrase repetitions. This occurs just as they begin to emulate adult speech patterns. In their effort to produce more complex language and thoughts, they may increase their rate of speech, have problems with fluent delivery or increase their sound articulation errors. This should not be called stuttering and parents should consult with a speech-language specialist to better understand how to respond when these behaviors occur.

Q. Should I correct my child's language and speech errors and make him repeat the correct version?

A. Your child would benefit more if you spoke to him at a slower rate, and used shorter, less complex sentences. Model correct versions of the child's error but do not make him repeat it. This indirect correction method is more helpful and less stressful.

Q. The results of testing indicated that my child's language is delayed. Is it my fault? Is my child retarded?

A. Though some research has suggested the notion of genetically based language disorder, the research is far from conclusive. Parental fault is rarely valid as the explanation, and parents should seek a fully professional evaluation of their child's language delay before assuming their child is retarded.

Q. What can I do to make sure that my child's language develops normally without pushing too much?

A. Parent-child play and story telling are two of the best sources that can be relied upon as natural ways to enrich a child's language. These can be accomplished in a relaxed environment with minimal stress and expense.

Illustrations by Leah Spring

NEXT ISSUE: Your Child and School

Special Parent ★Special Child

Practical pointers for parenting handicapped children

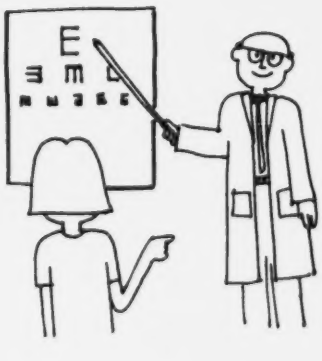
VOL. 1, NO. 5 SEPTEMBER/OCTOBER 1985

GETTING YOUR CHILD READY FOR SCHOOL

Going to school is one of life's milestones. School is perhaps the most important venture into the real world. Most parents view their child's school days with mingled feelings of anticipation and trepidation. It reflects their feelings about their own school days. Memories are stirred—fears of getting lost, of not belonging. At the same time we remember the joy of learning, making friends, a wonderful teacher who guided us.

Now that the first day of school is approaching, chances are all your children are excited, eager, a little afraid . . . and so are you. In this issue you will be given pointers on how to make your special child's school experience as happy and successful as possible.

Do's and Don'ts



Do get your special child off to a good start with a physical examination. Now is the time to have his eyes checked and to mention to your doctor any health problems that might interfere with learning—frequent colds or runny noses, ear infections, possible allergies.

Do keep good records. This is vital for your child as he moves through the special education process. It is more than likely that you will be frequently asked for your child's immunization records, psychological evaluations, teacher reports. Start a file with your child's name on it and **keep those records handy.**

Do make sure you understand the terminology used by the professionals dealing with your child. Ask them to translate the terms into layman's language. This will avoid misunderstandings and confusion about your child's abilities and those areas where he requires help.

Do make sure your child can separate from you easily. A child who cannot adjust to being without your presence or protection will find it difficult to adjust to a new teacher, or a new school, or even new classmates. Practice by leaving your child in someone else's care—for a short time at first and then for longer periods.

Do help your child learn to take care of his own needs. This is not as simple as it sounds. Hanging up your child's clothing for him, or dressing him may take less time than having him do it himself, but will cause problems in school if his teacher must

ABOUT THE AUTHORS

Linda Murphy, M.S., is the founder and for the past 15 years has been the director of a widely known, approved school for mentally handicapped children serving children ages 5-21 in Westchester County, NY, and surrounding areas. A lecturer, teacher and administrator, she is a foster parent and the parent of a handicapped child, too.

Suzanne Della Corte, M.S., for 15 years co-director of the school, is responsible for curricula, staff development and supervision. She is author of numerous research projects in the field and has edited psychology textbooks for a leading New York publisher.

always assist him. Try to select clothing that is easy to take on and off. Praise and reward all your child's efforts at self care.

Do give him a chance to learn responsibility. Putting away his own toys, taking out the garbage, feeding the family pet are activities that teach responsible behavior which is necessary in group settings, especially school.

Do make sure your child gets used to being told what to do. A child who cannot accept the teacher's directives will be quickly labelled a "behavior problem." Practice having your child follow simple directions at home such as coming immediately when called. Always praise his efforts.

Do familiarize your child with school language. Many times special children are confused in school because they do not understand the terminology. Not knowing the meaning of "line-up," for example, or "boy's room" instead of bathroom can add to your child's apprehension. Make sure your child understands as best he is able words such as: water fountain, gym, cafeteria, library card.

Do help your child with school lunch routines. Practice ahead of time how to open and close a lunch box, drink from a milk carton, unwrap a sandwich, pour liquids from a thermos. If his school serves hot lunches, teach him as best he can how to handle a tray and pay for his food. Fast food restaurants are excellent places to try out these skills.

Don't let mornings frazzle your nerves. A child who gets in the habit of dressing before breakfast will have fewer problems getting ready for school. Remember that many special children have fuzzy concepts of time and no way of determining how long it takes to complete activities. Your cries of "hurry up, hurry up, your bus is coming!" probably have little meaning to your slowpoke. If such inadvertent dawdling is making your mornings a misery, try using an oven timer. Reward your child with special praise for being dressed by the time the bell rings.

Do dress your special child like everyone else. Look around and see what is considered stylish for other children your child's age. If jeans and sneakers are in fashion, make sure your special child's wardrobe features these items. All children like to belong and looking like one of the gang contributes to the feeling.

Don't forget to talk to your child about his school days. It's important for your special child to share his school experiences with you. Listen carefully and ask questions about how he is getting along with others and how he feels about school. If your child has trouble communicating, perhaps his teacher can drop you a note to keep you up-to-date.

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Don't wait until serious problems occur before contacting school. If your child seems unhappy or frustrated, don't hesitate to contact the school immediately. Many times a minor problem can be solved before it becomes a crisis if home and school work together from the beginning. Talk to the teacher, find out what the school policy is concerning home-school contact or telephone conferences. Alert the teacher to any problems you feel are important.

Do take advantage of parent-teacher conferences, open school night and other school-related activities. Home and school should get together on what is asked of your child. If you know what is happening at school, you can develop a consistent approach towards your child at home. Knowing about what goes on at school can extend and enrich his school experience. Talk to other parents and join the parent organization if there is one.

Do set up a home-study routine from the very beginning. Get your special child into the habit of sitting quietly and doing such things as coloring or looking at a book. Setting up this type of quiet time for the whole family enables siblings to get their homework done and gives your special child a sense of participation.

Do adopt a positive attitude! If you have positive feelings towards school, chances are your child will, too. Help your youngster understand that differences are not bad. Help him to think of his problems as things that can be overcome and that school is the place where people are working to help him help himself.

The first days of school herald a new beginning. Shiny new shoes and sharpened yellow pencils are for everyone. With your help, your special child's school experiences can increase his joy in life.

Words you should know

(cont'd on p. 4)

in those processes affecting their child. Parents **must** receive written notice, be given opportunities to participate in the decisions, and be granted the right to review, agree or disagree, consent or deny the plans for the education of their child **before** they can be carried out.

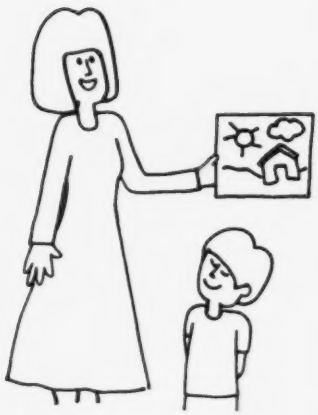
- **Impartial Hearing.** A hearing that may be initiated by either the parent or the school district should disagreements arise as to the recommendations made about the child's educational program, or should the parent refuse to give consent to recommended programs or evaluations. An impartial hearing officer makes the decision. If the parent contests this decision, an appeal to the State Commissioner of Education or a review by the courts may be in order.
- **Multi-disciplinary Team.** Professionals from several different disciplines (psychology, education, social work, speech, medicine) who jointly make assessments and recommendations about your child's program.
- **Least Restrictive Environment.** A school must, to the maximum extent appropriate, provide for the education of a child in a regular school setting with children who are not handicapped.
- **Mainstreaming.** A child who is designated handicapped must, to the maximum extent appropriate, be placed in a class with regular children for all or part of the day.
- **Related Services.** Support services such as speech therapy, psychological services, counseling, physical or occupational therapy. Children receive this help for a number of periods a week, depending on their needs.
- **Special Class.** A class designed for children who have been grouped together because of similar educational needs.
- **Resource Room Program.** A special education program for a child in a regular class who is in need of supplemental instruction in an individual or small group setting for a portion of the school day.

Getting yourself through the special education maze

by Ettore N. Piraino, Ph. D.

A parent once observed that she felt like David fighting Goliath when it came to dealing with her school's refusal to provide her son with speech therapy. While we know the outcome of David's battle, dealing with the school bureaucracy is not predictable. It helps, however, to arm your "slingshot" with knowledge about federal laws which guarantee specific rights to handicapped children and their parents. This is not to imply that all your relationships with the school should be adversarial, but rather to build your sense of confidence when working with school people.

KNOW your child has a right to a free and appropriate education. School districts can put you on the defensive by making you feel they are doing you a favor by taking care of your child's special needs.



ASSERT your child's right to a free education in the lest restrictive environment.

Here are your child's rights under Public Law 94-142 Education for All Handicapped Act. Remember that this federal law guarantees your special child will be appropriately referred, evaluated and placed in a school program that meets his needs.

REFERRAL starts the process of determining whether your child is in need of special education. If there is a reason to believe your child is learning disabled, emotionally disturbed, speech or language impaired, hard of hearing, deaf, visually handicapped, mentally retarded, orthopedically impaired, or other health impaired, then you, a school person or a physician can refer your child to the mandated multidisciplinary team for a complete EVALUATION.

Make sure to keep copies of everything concerning your child and insist the referral is in writing.

EVALUATION means tests administered and discussions held to determine factors affecting your child's school performance. In the evaluation process you have a right:

1. To know that an evaluation is being planned before it occurs. Brian came home recently and told his mother that a funny lady he had never seen before took him out of his second grade class, brought him to a room alone, and gave him a test with blocks and picture puzzles to do. Since his mother knew nothing about this, she called the principal, told her to stop the testing, and requested a conference to find out what was going on.

2. To know the content of the evaluation. You have a right to know what tests are being used, how they will be used, and whether they have been evaluated for cultural bias. Tests must be given in your child's dominant language. A good assessment will always consist of an individual psychological examination, a physical examination, a social history, and an assessment of the area of suspected disability. All testing should be given on an individual basis by trained personnel in quiet, comfortable rooms at a time of day when your child is most alert.

3. To give or deny consent for the testing. No one has the right to conduct an individual evaluation without your approval. Give your permission only after you are satisfied that the evaluation will be appropriately carried out.

4. To obtain an independent evaluation outside of school which you are prepared to pay for. The school must pay if you can establish that the school's evaluation is inadequate.

5. To be informed of all your rights at the time permission for the evaluation is requested.

6. To be accompanied to school meetings by whomever you choose to help you with this process. DO bring along a friend, family member, clergyman, child advocate, educational specialist, etc. DON'T go it alone. These are stressful experiences. No one functions at their best when stressed. Having a supportive person with you helps to reduce the stress.

PROGRAM AND PLACEMENT are recommended to the Board of Education by the multidisciplinary team after the EVALUATION is done.

At this stage you must receive a copy of the test results and an explanation of their meaning. Within 30 days of the original

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referral, your school must have a meeting to determine whether or not your child has a handicapping condition. This meeting is called the IEP meeting (Individual Education Program) and must be conducted by the multi-disciplinary team.

THE IEP team develops the Individualized Education Program which includes your child's:

- present levels of educational performance
- annual goals
- educational services to be provided, e.g. resource room, special class, special school
- related services such as transportation, speech, language therapy, counseling, physical and occupational therapy, recreational therapy
- extent of mainstreaming
- when the services begin and how long they will last

Where PROGRAM takes place is the PLACEMENT. The law gives handicapped children the right to remain in regular school settings (which is the least restrictive environment) if supplementary services permit them to function satisfactorily in that setting.

If the program cannot be carried out in the local school, the Board of Education can, if the team recommends it, place children in neighboring school districts, regional cooperative programs or private schools. The IEP is the heart of the special education process and should be reviewed very carefully.

You are guaranteed the RIGHT, by federal law PL 94-142 to **equal** participation with school personnel in the development of the IEP. This is the stage at which there can be disagreement as to the appropriateness of the educational program and related services prescribed for your child. Your opinions have equal weight with the school people. Insist on being heard.

You must give consent before the IEP can be implemented. DO consult with others. DO read the IEP carefully. DON'T grant consent at the team meeting before you have time to review the written IEP.

The school must provide you with an **impartial due process hearing** if you disagree with the recommendations of the team. Consult an expert in the field, or an attorney who specializes in such cases if you reach this stage.

The team must formally review your child's IEP at least once a year, and revise it if necessary. You must be given notice and invited to participate in the annual review. You have the right to request a meeting of the team whenever you think the IEP needs revision.

REMEMBER all of the above is guaranteed to you by federal law. The Supreme Court has upheld the provisions of PL 94-142 in numerous decisions. Go to your local law library and ask for the "Code of Federal Regulations (CFR) Title 34" and look up Chapter III: Part 300, Appendix C to see if your state and your school are doing it right.

DO be assertive. Schools do not grant equal participation rights easily. It is still a fairly new concept for them. But being unpopular may be a small price to pay in order to ensure an appropriate education for your child. Good luck to all the "Davidas" and "Davids" as you work for a free and appropriate education for your child.

SOURCES OF HELP:

Orton Dyslexia Society
International Headquarters
724 York Road
Baltimore, MD 21204
(301) 296-0232

REPRINTS AVAILABLE

- Behavior, Part I
- Behavior, Part II (Eating, Sleeping)
- Speech: Helping Your Child Communicate
- School's Out! It's Time To Play

Association of Children with
Learning Disabilities
4156 Library Road
Pittsburgh, PA 15234
(412)341-1515

Council for Exceptional Children
1920 Association Drive
Reston, VA 22091
(703) 620-3660

Your State Education Department
State Capital

Psychologist's Corner: SCHOOL PHOBIA

by George Popper, Ph.D.

Many children have fears that, in most cases, seem to be part of growing up and which disappear as the child gets older. But sometimes these fears are exaggerated to the point where the child has difficulty functioning. For example, one child might be afraid of dogs and avoid them, while another might be so fearful of being bitten that he refuses to leave his home. This latter example describes a child who has a **phobia.** A phobia is an extreme, usually irrational, fear of a particular object or situation, and a child exhibiting **phobic behavior** goes to great lengths to avoid the object he fears.

How do children develop phobias? One theory has it that even simple admonitions from parents to "watch out" can lead to the development of a phobia. Sometimes, parents who themselves are phobic, transfer their fears to their offspring.

Perhaps the most upsetting (and disruptive) of all phobias is school phobia. Usually, this phobia involves a steadfast refusual to go to school, or extreme anxiety exhibited either at school or at the mere thought of school. Often the anxiety is accompanied by a variety of physical complaints such as a sore throat, stomachache, vomiting or headache. School phobias occur equally among boys and girls and are sometimes associated with classroom experiences. For example, some children might be overly sensitive to ridicule, as in the case of a girl who is developing breasts or a boy whose voice is changing, so that their fears become school phobias. Some parents feel that they are to blame for their child's school phobia, but this is rarely the case. In fact, no one really knows why or how these phobias develop.

What can you as a parent do to help your child overcome the phobia? The best thing is to get your child back to the classroom as soon as possible, but **don't** use force or threats. Make the teacher and principal aware of the problem as soon as you see evidence of it. You will need their help and cooperation to work with your child in solving this problem.

Remember that just as your child did not develop this phobia or fear overnight, so too it will not disappear overnight either. It is essential for you to remain calm and to provide understanding and reassurance to your child. I suggest a gradual desensitization:

- Do accompany your child to school and **sit** with him in the classroom.
- Gradually shorten your time in the room with him.
- If necessary, wean your child from your presence in the classroom but **stay** in the school and make sure your child is aware of where you are.
- Above all, be reliable and punctual. Always come back to him precisely when promised. If you tell your child you will be at the classroom door to pick him up at noon, make sure you are at the

school early so as to arrive at the classroom door **exactly on time**. Your child needs a strong sense of security and your promptness provides him with that.

- Don't discuss the phobia at length and, above all, never negate your child's expression of the fear.
- Don't ridicule or refer to your child's difficulties at being childish or foolish or for "acting like a baby."
- Don't compare your child to younger children who are adjusting normally to the school environment.
- Speak matter-of-factly and positively about the school and classroom.

If, after a time, these efforts are not successful in alleviating your child's fears, don't hesitate to seek professional help.

THE READER ASKS . . .

QUESTIONS AND ANSWERS

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Special Parent/Special Child
Lindell Press, Inc.
P.O. Box 462
South Salem, NY 10590

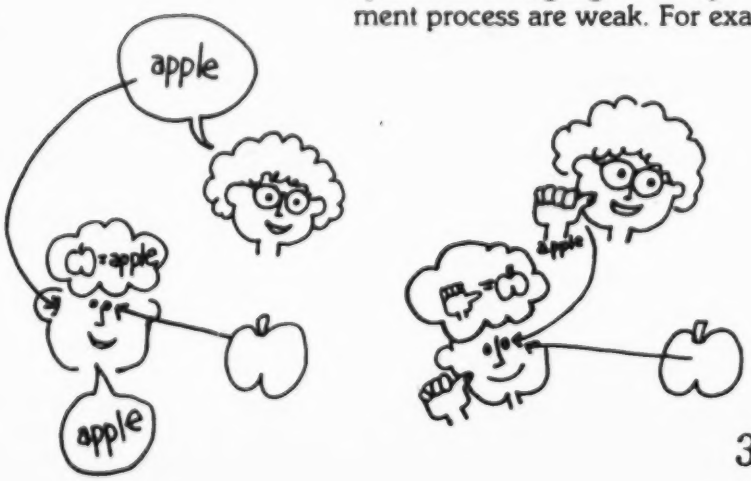
Q. I read your recent articles on speech. My daughter, age six, has trouble talking. Now her school tells me she should learn some kind of sign language. My girl is not deaf. I'm confused and upset that if she starts talking with her fingers, she will stop talking out loud and never speak. What do you think?

A. The editors have asked Leah Spring, a teacher of communication disordered children, to reply.

"Many people believe that sign language is a method of communication used only by the deaf. However, it is also widely used by children who have difficulty communicating verbally. There are a variety of reasons why a child may not be speaking, depending on which links in the speech and language development process are weak. For example, your child may hear well but be unable to make sense of the language in the world around her. Perhaps she understands everything that you say to her but has difficulty learning, remembering and/or producing the words or ideas that she wishes to express. Whatever the cause, the most important thing we can do for your child is to give her a way to communicate these needs. When we teach her to talk with her hands and to watch us talk with our hands (rather than listen), we are bypassing weak areas of development and giving her a way to reach out to us. Encourage your child to speak to the best of her ability as she signs. Studies show that this method may help her verbal skills to develop and sign langage may later be dropped. Meanwhile, your child's frustration at her inability to be understood is alleviated.

"For any communication program to work, parents and teachers should work together closely. Ask your child's teacher to provide a list of words she is working on at school. She should also refer you to her source of sign language as signs vary from book to book."

Good luck!



Illustrations by Leah Spring

Special Parent ★Special Child

Practical pointers for parenting handicapped children

VOL. 1, NO. 6 NOVEMBER/DECEMBER 1985

FOCUS ON: THE FAMILY

In order for families to function effectively, the needs of **every** family member must be met. In families where there is a special child often the focus is on caring for and meeting those special needs to the detriment of others. In this issue we will explore ways to maintain the balance necessary to enrich and enhance the family unit as a whole.

With the holiday season approaching, more attention is paid to family activities and togetherness. Relatives are apt to visit and there are more occasions such as church, holiday dinners, social events where families are likely to convene. Often family get-togethers can be taxing and now more than ever you will have to take into consideration your special child's disability.

Siblings

You probably have had misgivings all along or have secretly worried that your concern for the unique needs of your special child has led you to neglect your other children. If this is so, remember that these feelings are entirely natural. There ideally should be a sensible use of family resources and a sharing of mutual concerns. It will take some effort but there **are** many different ways you can work toward this.

Do's and Don'ts

Do set up family meetings on a regular schedule when all members can be present. Establish an atmosphere where all family members, including yourself, can air feelings or express anger openly and honestly. If problem areas are discussed in this fashion, it is less likely for the normal sibling to feel left out or conclude that their special brother or sister is favored.

Do recognize no matter how much siblings love their special brother or sister they are bound to have conflicting feelings. Often siblings feel guilty that their brother or sister is handicapped and not they. At the same time they resent all the attention their special brother or sister receives.

Do realize that a child with guilty or angry feelings needs to be able to talk about these conflicts with someone who understands—and who is not shocked. When you sense your child is upset, help him by saying: "You're upset about your brother today. It's hard not to get upset. I understand. I feel like that sometimes, too. It's only natural."

Do talk openly and honestly about the nature of your special child's disability. If everyone in the family understands the extent of the disability and exactly what it means, they will be less likely to become embarrassed. When siblings are able to explain their special brother or sister's disability to their friends it helps their friends to accept him or her too.

Do make a concerted effort to keep your other children abreast of the condition and needs, medical or otherwise, of their special brother or sister in practical, non-threatening terms. This will ease their guilt and possible resentment. The more they know, the better equipped they will be in handling their feelings.

Don't expect your normal children to include their handicapped sibling in all of their activities. They need time just for themselves, too.

Do share the care. Allow your other children to help their handicapped sibling for certain **designated activities.** This helps to ease their guilt without actually overburdening them.

Don't burden your oldest. In many instances the oldest child is often singled out as the caregiver which can cause resentment. If there are several siblings, make each one "Officer of the Day," and assign certain tasks connected with their handicapped sibling for **that day only.**

Husbands and wives

The presence of a handicapped child more than any other factor poses a serious strain on marital relationships. A child, after all, is a reflection of oneself—one's hopes, dreams and ambitions. Try as we may avoid doing so, we tend to live vicariously through our children. When one's child is disabled, our hopes are dashed and we are left too often with only guilt and sorrow. Unhappiness over the child tends to spill over and color the fabric of the marriage. It's hard then to distinguish if the problem is with the child or the marriage.

Do's and Don'ts

Do listen to each other. Both husband and wife need a chance to sound off, to complain, to yell and even shout "why me?" If this is done in an honest and open atmosphere of ventilation rather than bitter recrimination, it gives both a chance to share and team together, rather than oppose one another.

Do divide up the chores. This sometimes requires a juggling of time and talents and the reversal of traditional male-female roles. For instance, father might get the normal children off to bed, including bath and bedtime story, while mother attends to the special child or vice versa. Turn-taking is the best and fairest method. Marketing, errands, laundry, cleaning, meal preparation are all facts of family life. If one spouse prefers to plan menus and market, then perhaps the other spouse can tend to clean-up

ABOUT SPECIAL PARENT/SPECIAL CHILD:

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chores and babysitting while those errands are tended to. Sharing the responsibility for household chores gets them done more efficiently, and leaves more time to be together and relate to each other as husband and wife.

Do get everyone off to bed at a firm but reasonable bedtime hour. This will enable you to spend quiet moments in the evening together.

Don't underestimate how tired you both are. Caring for a handicapped child, even in the best of circumstances, is a monumental, exhausting job. You may not even recognize how fatigue affects you. Snappishness, easily-hurt feelings, difficulty in concentration, tears-close-to-the-surface are all sure signs of fatigue. Fatigue magnifies problems and becomes a vicious cycle of fatigue-escalating problems-more fatigue. Recognize that this is why you feel the way you do. Even if you can't do much about it, sometimes knowing why eases the problem a bit.

Don't feel guilty about finding time, space and relaxation for yourself. If possible, avail yourself of babysitters or respite care. Hire a college student to live in, investigate homemaker or home-health-care services in your area. Your relatives or your neighbors might be willing to pitch in, especially if you are honest and ask for some help.

Don't isolate yourself. It's easier sometimes to remain in the privacy of your own home away from strangers' prying eyes. When you isolate yourself and your handicapped child you are cutting off normal relationships for the rest of the family. Give the outside world a chance to get used to your special child. By doing so you can dispel a lot of the myths and fears surrounding the handicapped.

Do seek mastery and competency outside of the house. If you can succeed in an area outside of child care that is totally your own, chances are your increased self-esteem will give you that extra boost to return to your handicapped child **and** marriage with a refreshed outlook. Part-time employment, volunteer work, active membership in church or political party, or parent organization will lift your spirits and encourage you to go on.

Do put spontaneity back in your life. Go out—just the two of you—if only for a drive. Hire a babysitter and go out for a dinner, a movie, any activity you can both share and gain pleasure from.

To Grandmother's house we go . . .

The holiday season is the time of year when there is more family togetherness. Often family relationships are not the sources of support that ideally we expect them to be. Relatives can be unintentionally cruel and the oft-heard remark of "This doesn't come from my side of the family," referring to your special child, can hurt to the quick. Well-meaning suggestions about cures, treatments, vitamins working wonders, can be tiresome. Criticism about your methods of child care and discipline can also be discouraging. If you sometimes find family functions to be draining experiences, try the following:

Do's and Dont's

Do respond to comments blaming the other side of the family with the measured response: "That's very interesting. You are concerned about where John's disability comes from. However, that doesn't change either John's condition or his disability one bit." If you repeat this often enough, chances are the relatives will tire of this line of inquiry. Your calm tone of voice will also let people know you are in control of the situation.

Do be sure your relatives understand the nature and extent of your child's disability. To know, for example, that their grandchild has something called cerebral palsy tells the grandparent little about the dysfunction, the treatment, what to expect, or what they can do to help. Explain to them, in simple concise terms, factual information about the disability.

Do recognize that grandparents initially feel pain and sorrow when their grandchild, symbol of their immortality, is disabled. They need to know when and how to help—and gain joy from their special grandchild.

Do make sure that relatives know they can help, too. If the relatives know all the ins and outs of communicating with and caring for your special child, they would probably be less fearful of doing something wrong and more willing to give you the needed assistance.

Families **can** be a rich source of comfort and support given the chance and if everyone is open and honest in their communications.

Where to get help

If there is strain and tension in the family, it will help to get regular counseling from an understanding social worker or other supportive professional. To find such help contact a local accredited hospital, your public health department, or look up "clinics" in the yellow pages. You can write to:

National Association for Mental Health
1800 N. Kent Street
Arlington, VA 22209

Council for Exceptional Children
1920 Association Drive
Reston, VA 22091

American Psychological Association
1200 17th Street NW
Washington, DC 20036

Join a parents' group or organizations for the handicapped. Talking with other parents who have similar problems and who have found solutions can be extremely helpful. For a list of parent organizations in your area write to:

National Special Education Information Center
P.O. Box 1492
Washington, DC 20013

Practical Pointers

1. Set aside time for your normal children. They need your undivided attention at times, too.

2. Give your special child family chores. It will make your disabled youngster feel he is contributing and will ease the resentment of the other children. It will take ingenuity on your part, but it is worth it.

3. Avoid the "I can do it faster myself" habit. Of course you can, but remember your special child is entitled to participate and gain skills in activities of daily life.

4. Include your special child in as many family activities as possible—as long as this does not present significant problems. For example, having your special child hold the prayer book at church gives him a sense of participation and self-worth even though he might not understand the service.

5. Don't be ashamed to ask for help. Join a parent organization or similar support group. Talking to other parents is a rich source of people who've been there and who perhaps have solved some similar problems.

PARENT-TO-PARENT

From time-to-time the editors would like to share with our readers news of parent support groups throughout the country who are providing outstanding service. This issue we are highlighting "We've Been There," a West Virginia parents' group, and the "International Rett's Syndrome Association," a group of parents whose children suffer from a rare malady which at onset mimics infantile autism.

"We've Been There"

by Joyce F. Altizer

"It was a horrible blow to be told my daughter had a birth defect. My sanity was dangling by a slender thread. Talking to an experienced parent helped me realize that Pandora's box of thoughts and feelings was normal. Up until the veteran parent visited I felt bad. When she left I felt more confident that I could face and handle it. What a relief to know I could call her and she would listen and share practical ideas and options. It helped a lot just to hear that there were people and programs to help me help my baby."

Parent-to-parent support is not a new idea but in West Virginia there was no formal network for parents of newly diagnosed children with disabilities until recently.

Our project began because the West Virginia Advocates for the Developmentally Disabled (WVADD) travelled the state for many years and consistently heard professionals and other parents express concern about families who were not involved in their special children's education. It seemed to them that these parents "didn't care" about their children. WVADD did not believe the lack of parental input was due to not caring or a character flaw. Rearing a child with a handicap is hard and many parents feel stigmatized and intimidated.

We strongly believed that right from the beginning parents need emotional support, a channel to vent their fears and frustrations, and an opportunity to get practical and accurate information from people who understand. Who could better understand than a parent who has been in a similar situation?

With these beliefs, a grant was awarded by the state to develop a model of parent support and generate similar programs throughout the state.

IN FUTURE ISSUES LEARN ABOUT:

- Those Psychological Tests What Do They Mean?
- Sex Education
- Managing Your Child's Medical Needs
- Behavior Modification

Plus much, much more!

REPRINTS AVAILABLE

- Behavior, Part I
- Behavior, Part II (Eating, Sleeping)
- Speech: Helping Your Child Communicate
- School's Out! It's Time To Play

"We've Been There" matches trained veteran parents with parents of newly diagnosed children to (1) offer moral support; (2) link the family to programs and services; and (3) provide accurate information about the nature of the problem. We stress the potential and worth of children who have a handicap.

As peer helpers, veteran parents supplement what professionals do to assist families. Parents who have made a good adjustment to their situation have something unique and valuable to share. Their message is "It's tough but you can do it. Hang in there!"

Knowing the value of support and remembering feeling overwhelmed and devastated, veteran parents volunteer their time to try to make it "just a little easier." The moms and dads are warm, nonjudgmental people who are eager to share lessons learned through their experiences.

As a result of "We've Been There" and other parent support groups, parents are beginning to realize they are not alone, that they can exercise control in their lives. This year, due to strong parent advocacy, the West Virginia legislature passed a bill to educate pre-school handicapped children.

A videotape series Parents-to-Parents produced in conjunction with the project features West Virginia families from all walks of life openly and honestly discussing how they've coped. Each of the four tapes—"Grief," "Denial," "Guilt," and "Anger"—demonstrates that the problems are seldom insurmountable. Their message to parents is one of hope, encouragement and comfort.

When a parent receives positive support from people who have experienced similar things, when they are given practical information about their child's condition, and when they get linked to services early—then families feel better about themselves, their child, and their future.

Parent support projects now operate in 11 West Virginia counties and we are constantly receiving calls from other areas expressing interest in building parent support groups.

Being involved in a parent-to-parent program boosts parent confidence. Parents learn to express their opinions and observations. These projects are advocacy in its most basic form.

For more information about "We've Been There" or the videotape series, contact:

WVADD
1200 Quarrier Street, Suite 27
Charleston, WV 25301
(304) 346-0847

International Rett's Syndrome Association

We have recently begun an organization for parents, professionals and other supporters interested in Rett's Syndrome. The aims of the International Rett's Syndrome Association are to provide direct support to other parents, and to find ways to encourage research that may provide answers to our long-held questions about our children's developmental difficulties.

At present, there are over 150 children represented in our membership. There are at this time only 200 known cases of this syndrome worldwide, but it is thought to be as prevalent as one in every 15,000 births, based on studies in Sweden.

Rett's Syndrome is a disorder which strikes only girls. It has, for the most part, gone undiagnosed

ABOUT THE AUTHORS

Linda Murphy, M.S., is the founder and for the past 15 years has been the director of a widely known, approved school for mentally handicapped children serving children ages 5-21 in Westchester County, NY, and surrounding areas. A lecturer, teacher and administrator, she is a foster parent and the parent of a handicapped child, too.

Suzanne Della Corte, M.S., for 15 years co-director of the school, is responsible for curricula, staff development and supervision. She is author of numerous research projects in the field and has edited psychology textbooks for a leading New York publisher.

in this country for the last twenty years, although it has been recognized in Europe since 1966, when Dr. Andreas Rett of Vienna, Austria, described the syndrome.

Girls afflicted with the syndrome appear normal until seven to eighteen months, but then appear to arrest in development or regress in previously acquired skills. They exhibit the autistic features of withdrawal and isolation in the early stages of the disease, but these features improve with age. In about two-thirds of the children, seizures develop. Deterioration of higher brain functions leads to severe retardation and children experience a slowing of head growth. The children lose the purposeful use of their hands and replace it with a constant, stereotyped "handwashing" movement in front of the face or chest.

The children who walk do so with a broad-based gait. They often exhibit shakiness of the limbs and torso, grinding of the teeth, and grimacing of facial features. When they reach their teenage years, the symptoms include spasticity, curvature of the spine, poor circulation in the legs and loss of walking mobility, if developed by that time.

Extensive laboratory investigations have not revealed a cause for Rett's Syndrome, but there is a suggestion that as the syndrome is confined to girls, it may indicate a genetic basis involving the "x" chromosomes. More research is needed in all areas.

For more information, interested persons may contact:

Kathy Hunter, President
International Rett's
Syndrome Association
8511 Rose Marie Drive
Fort Washington, MD 20744

Psychologist's Corner: FIGHTING THOSE HOLIDAY BLUES

by George Popper, Ph.D.

Holidays are usually times of happiness—families get together to celebrate or simply to enjoy the company of close friends and loved ones. But holidays are not all fun and games. There are many who view holidays with fear and trepidation. They anticipate having children home from school, a house full of company and a mess. To them, holiday-time is work-time. Parents of special children have added problems and concerns. Here are two of the more commonly raised questions along with some suggestions which might make your holidays a bit easier to take.

"It's the holidays. I'm supposed to feel happy, but why do I feel so down?" Believe me, you're not alone. There are a surprising number of people who feel the same way you do with the "holiday blues." There are many reasons why people feel that way. People become depressed or unhappy when their expectations of something fall short of reality. Remember that feeling "blue" around holidays is not unique, but also remember that it's not necessary. Think of holidays as a time to enjoy yourself and try to take them a little less seriously. Perhaps the best suggestion is the most obvious. Don't be alone and do plan something to do. Make your plans far enough in advance to forestall any unanticipated problems. Be reasonable. Avoid situations that are too extravagant or complicated. Perhaps doing something you've never done before or something that's a little different might be what is needed. You might end up with some actual problems, but at least you'll have fewer imaginary ones.

"Every time we have company, my 'handicapped child' acts up and manages to embarrass me. What can I do?"

Actually, there are several reasons why children "act up" in front of company and these reasons are not limited to handicapped children.

Sometimes, children behave badly when something unexpected happens to them, or even if their routine is disrupted. One way to handle this situation is to avoid surprises. Prepare your child in advance, letting him know who's coming and what will be happening. Give your child a chance to respond and ask questions. Take the time to deal with any fears he might have. Do it far enough in advance so that you'll have time to talk to your child but not so far that he'll forget. It's also helpful to prepare your guests. It's not that you're anticipating a problem, but if something happens, people will at least be able to understand. It might also be helpful to remind well-meaning grandparents and relatives to be supportive of your role as a parent. It's worthwhile to get everyone's cooperation. Make sure everyone praises and rewards your child when his behavior is appropriate and ignores him when it is not. This kind of simple behavioral training is very effective when it is used with all your children all the time.

Most importantly, don't go it alone. Have someone to share the responsibility with you and make sure everyone knows what to do in advance. Having a reliable backup is essential. If you are a single parent, a sibling, friend, relative or even a hired helper will do just fine.

THE READER ASKS . . .

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Q. What do I do when my school district tells me "It costs too much money," or "We don't have the class" that my child requires?

A. PL 94-142 Education for All Handicapped Children Act is a federal law that insures a free, appropriate public education for all handicapped children. Lack of funds is no longer a valid excuse. States receiving federal money **must** comply. If your local school district does not have a class that meets your child's unique needs, your district, with your consent, can place your child in a neighboring school district, a cooperative (joint) school district or a private program. Contact your State Department of Education for help.

Q. I've read several issues of Special Parent/Special Child and have found it very helpful in the problems I have with my retarded son. I use the Do's and Don'ts column with my normal son, too!

A. Many readers have made similar comments. The needs of special children differ from normal children in degree but not in kind. First and foremost a handicapped child is just that—a child. All children, normal or otherwise, respond to guidance, instructions and parents who can **limit as well as love.** We are pleased to know we are helping.

Q. My child wants to brush his teeth by himself, but his grasp is too weak. Can you give me some suggestions?

A. Try putting the end of the toothbrush through a small sponge ball for easier grip. If his grasp is too weak for effective brushing, use a battery-operated toothbrush along with the sponge ball.

Illustrations by Leah Spring